



Société Alzheimer Society

CANADA



Fondation
Brain Canada
Foundation

‘Dying on Our Own Terms’: Promoting Relational End-of-Life Dementia Care



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STIGMA ASSOCIATED WITH DEMENTIA & END-OF-LIFE

- Committed to challenging stigma associated with dementia and to fostering relational caring
- Urgent need to improve the end-of-life experiences of people living with dementia and their family members
- Very little research conducted on end-of-life and dementia
- None that includes the perspectives of all involved in end-of-life experiences





OUR TEAM

- Joshua Black, BC Centre for Palliative Care
- Andrea Bridge, Person Living with Dementia
- Sandra Britten, Person Living with Dementia
- Charlotte Clarke, Durham University, UK
- Romeo Colobong, KITE Research Institute – UHN
- Heather Cooke, Alzheimer Society of BC
- Lynden (Lindsay) Crowshoe, University of Calgary
- Erin Delaney, University of Waterloo
- Sherry Dupuis, University of Waterloo
- Christiana Egi, Alexis Lodge
- Katia Engell, The Bitove Method
- Phyllis Fehr, Person Living with Dementia
- Rebekah Gold, Brock University
- Linda Grossman, Family Member
- Bill Heibein, Person Living with Dementia
- Mabel Ho, Social Worker
- Brenda Hounam, Person Living with Dementia
- Lynn Jackson, Person Living with Dementia
- Michelle Janisse, Alzheimer Society of Ontario
- Christine Jonas-Simpson, York University
- Debbie Keay, Person Living with Dementia
- Ginah Kim, Baycrest Health Sciences Centre
- Pia Kontos, KITE Research Institute – UHN
- Taylor Kurta, University of Waterloo
- Sian Lockwood, Partnerships in Dementia Care Alliance
- Kimberly Lopez, University of Waterloo
- Jessica Luh Kim, JLK Consulting and Coaching Services
- Roger Marple, Person Living with Dementia
- Erica MacTavish, University of Waterloo
- Myrna Norman, Person Living with Dementia
- Nina Okopiem, Alzheimer Society Brant, Haldimand Norfolk, Hamilton Halton
- Giulia Perri, Baycrest Health Sciences Centre
- Pamela Roach, University of Calgary
- Catherine Schalk, St. Clair O'Connor Community
- Allie Serota, Schlegel-UW Research Institute for Aging
- Stephanie Steh, University of Waterloo
- Leah Steinberg, Mount Sinai Hospital
- Nisha Sutherland, Lakehead University
- Marilyn Taylor, Person Living with Dementia
- Elaine Wiersma, Lakehead University
- Mary Beth Wighton, Person Living with Dementia
- Ann Marie Wilson, Family Member
- Sarah Wu, Alzheimer Society of BC
- Wan Xing (Crystal) Yang, Yee Hong Centre for Geriatric Care



OUR GOAL

- To examine what compassionate, relational caring at end-of-life looks like from the perspectives of people living with dementia, family members, and professionals from across the country with the ultimate goal to change end-of-life practices and improve end-of-life experiences for all those involved



PHASE 1: RESEARCH

- Analyzed existing policy and practice documents specific to end-of-life and dementia
- Conducted research conversations with:
 - 22 persons living with dementia in the community
 - 49 family members of persons living with dementia (in long-term care, the community, and bereaved)
 - 36 professionals from a range of settings
- Conducted 3 arts-based sessions with 20 people with dementia living in long-term care settings
- Our co-researchers living with dementia co-facilitated the research conversations with participants living with dementia



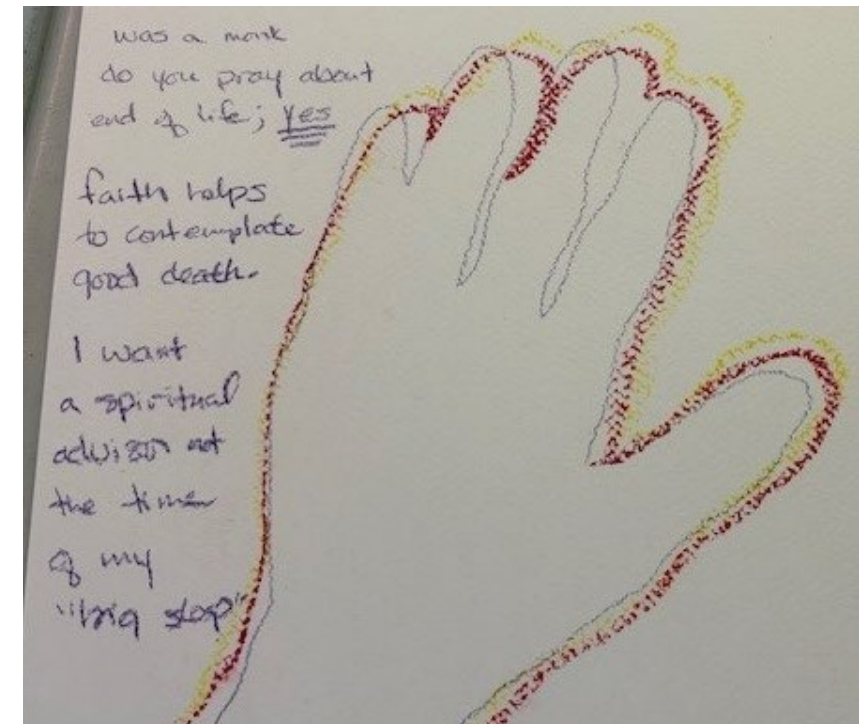
PHASE 1: RESEARCH

- We formed three analysis teams: a ‘persons living with dementia’ analysis team, a ‘family member’ analysis team, and a ‘health professionals’ analysis team
- All members of each analysis team read through research conversation transcripts assigned to them, completed work sheets based on their reading of the transcripts, and met together several times to explore the themes identified
- We brought all groups together to discuss and further refine the themes, which culminated in our relational end-of-life framework



LEARNING ABOUT AND RESPECTING THE PERSON LIVING WITH DEMENTIA (PLWD)

- Learning about the PERSON with dementia beyond the dementia diagnosis
- Understanding and honouring the PLWD's preferences for care at the end-of-life
- Respecting autonomy and the right for PLWD to have control over the dying process, including removing unnecessary treatments when desired
- Paying attention to the verbal and non-verbal (e.g., body language, facial expressions, etc.) ways PLWD communicate their preferences and experiences and assert their autonomy
- Educating the PLWD and their carers about the substitute decision maker role and ensuring the PLWD identifies their own substitute decision maker who knows, respects, advocates for, and communicates their preferences
- Dying with dignity while adapting to changing needs and co-morbidities
- Honouring and celebrating the PLWD's legacy and personhood after death





SUPPORTING QUALITY OF LIFE AND MEANINGFUL ENGAGEMENT

- Recognizing that PLwD can still experience joy at end-of-life, and providing joyful moments, peace, and fulfillment meaningful to the PLwD to the end of their lives
- Having/attending to physical, emotional, social, and spiritual well-being (e.g., providing emotional and grief support for PLwD; access to spiritual care providers)
- Prioritizing comfort as understood by the PLwD (e.g., effective pain and symptom management, considering both pharmacological and non-pharmacological therapies; addressing fears)





SUPPORTING FAMILY/RELATIONAL CONNECTIONS



- Learning about the family/others important to the PLwD, including their pets, and their needs
- Providing reassurance and emotional support to family members, recognizing that grief is an on-going, individualized process with no time boundaries
- Facilitating intimate time between the PLwD and others (e.g., family, friends, pets) at end-of-life if desired by the PLwD
- Providing knowledge and training for families to assist them in navigating end-of-life (e.g., knowledge of substitute decision-maker role, support at the bedside to help in understanding what they are witnessing)
- Providing practical supports/resources for family carers (e.g., financial, compassionate work leaves, etc.)



CREATING A COMFORTING ENVIRONMENT FOR PLWD AND FAMILIES

- Providing peaceful, familiar, home-like, surroundings meaningful to the PLwD (e.g., presence of comforting elements such as photos, plants, music; access to nature/outdoor spaces)
- Providing furniture that supports families to comfortably be present and rest nearby
- Prioritizing the social/relational preferences of the PLwD (e.g., wanting or not wanting to die alone, who should be there, having pets present)
- Having compassionate, respectful and understanding carers
- Having access to specialized end-of-life care (e.g., hospice, dedicated end-of-life spaces, in-home palliative care, death doulas, and MAiD)





NURTURING A SUPPORTIVE AND CARING HEALTHCARE CULTURE



- Ensuring leadership understands and supports relational caring at end-of-life
- Developing supportive policies and procedures aligned with relational caring at end-of-life
- Providing access to time and resources, including volunteers, necessary to provide compassionate relational caring at end-of-life
- Providing access to emotional and grief support for healthcare professionals
- Creating fulfilling jobs where healthcare professionals feel valued and recognized
- Providing ongoing training and education for healthcare professionals (e.g., dementia, relational caring, death and dying, advance care planning)



COMPASSIONATE, RELATIONAL END-OF-LIFE CARE IS SUPPORTED AND SUSTAINED BY...

- 1. Addressing stigma, prejudice, misunderstandings, and discrimination**
(e.g., associated with dementia and death/dying)
- 2. Nurturing strong relational connections between all involved**
(e.g., interdisciplinary approach; nurturing support networks; addressing relational conflicts)
- 3. Maintaining open, honest and transparent communication**
(e.g., early documentation and preparation for end-of-life; open end-of-life discussions; strong communication channels including use of technology)
- 4. Supporting relational caring practices and policies over the dementia journey**
(e.g., cultural awareness/humility; being responsive and flexible; consistency of care; staying up-to-date with current end-of-life care legislation)



‘DYING ON OUR OWN TERMS’: A RELATIONAL CARING END-OF-LIFE DEMENTIA FRAMEWORK

- Our framework advances a new compassionate approach to end-of-life care grounded in relational caring principles and inclusive of the perspectives of people living with dementia
- It identifies the components and supports to improve the end-of-life experiences of not only people living with dementia and their family members, but also the professional carers who support them at end of life





HEARING FROM OUR PARTNERS WITH LIVED EXPERIENCE

- Why is it important to explore end-of-life and dementia?
Why has this project been important to you?
- What are the most important messages about end-of-life and dementia that you want people to take away from this webinar?

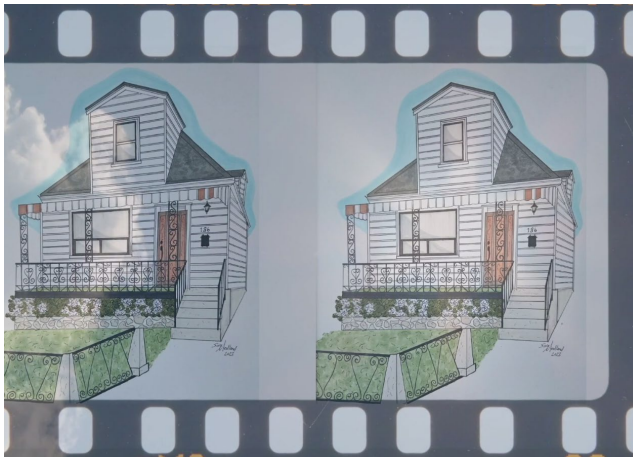
MOBILIZATION



PHASE 2: KNOWLEDGE MOBILIZATION



- **Digital stories** created by and targeted at people living with dementia and young carers





PHASE 2: KNOWLEDGE MOBILIZATION

- **Documentary films:**
 - One targeted at people living with dementia and family carers
 - One targeted at health care professionals





PHASE 2: KNOWLEDGE MOBILISATION



- **Policy and practice briefs** targeted at people living with dementia family member/carers, healthcare professionals/organisations, policy makers and other decision-makers



PHASE 2: KNOWLEDGE MOBILIZATION

- Interactive art scroll targeted at all audiences





VISIT OUR PROJECT WEBSITE



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Dying on Our Own Terms



Exploring compassionate, relational end-of-life care through the voices of people living with dementia, family and young carers, and professionals

Open conversations about death are often avoided, especially in dementia care, where stigma limits opportunities for people living with dementia to express end-of-life wishes and contributes to painful, over-medicalised, and undignified deaths. Existing research on dementia and end-of-life is limited and frequently excludes the perspectives of those living with dementia, despite end-of-life care being inherently relational and affecting persons living with dementia, families, and professionals alike.

This project addresses these gaps by exploring compassionate, relational end-of-life care through the voices of people living with dementia, family and young carers, and professionals. It aims to drive policy and practice change by sharing these perspectives through documentary film, digital stories, and practical resources, ultimately supporting a global movement toward more humane, relational end-of-life caring in dementia.

A Relational Caring End-of-Life Dementia Project

[uwaterloo.ca/
pidc/eol](https://uwaterloo.ca/pidc/eol)





THANK YOU!

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